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ABSTRACT

This feature issue of IMPACT focuses on the empowerment of families with a member who has a developmental disability. It presents strategies and models for a collaborative, respectful approach to service provision, and presents the experiences of families in seeking support and assistance. Feature articles include "Two Generations of Disability: A Family and Community Affair" (Vivienne Kaufman); "Decision Making in the 90s: A New Paradigm for Family, Professional, and Consumer Roles" (Jean Ann Summers); "Access to Services: Sharing the Power" (Fran Smith); "The Impact of Personal Futures Planning on Families" (Angela Novak Amado); "Advocacy: Noun, Verb, Adjective or Profanity?" (Linda Gress Bonney and Sandy Moore); "Self-Determination and Empowerment: The Parent Case Management Program" (Marijo McBride); "Empowering Rural Families: Two Success Stories" (one concerning a child with cerebral palsy, the other about an adolescent with traumatic brain injury--both contributed by the families); "Making the System Work: The Multicultural Family Inclusion Project" (Jamie Smith); "Family Mediation as Family Empowerment" (Patricia A. Moses); "Home-School Collaboration: A Building Block of Empowerment" (Mary F. Sinclair and Sandra L. Christenson); "Home-School Collaboration Model: Project FISC" (Cheri Gilman); "Family-School Collaboration in Interventions" (Michael Bloomquist); "Life Planning for Adult Health Care" (Timothy W. Jorissen); "Health Issues and Placement Decisions for Older Persons with Disabilities" (Deborah Anderson and Eric Kloos); and "Learning To Let Go" (Ceci Shapland). A resource list of 10 organizations, 2 videotapes, and 8 publications concludes the issue. (JDD)

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Family Empowerment

IMPACT; v5 n2 Summer, 1992

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IMPACT

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Feature Issue on Family Empowerment **Volume 5 (2) Summer, 1992**

Increasing numbers of families of persons with disabilities are gaining skills and knowledge in advocacy through programs such as PACER's Multicultural Family Inclusion Project. See story on page 10.

Two Generations of Disability: A Family and Community Affair

by Vivienne Kaufman

My preschool years were wonderful days of fun and games. But when school began, the nightmare began. I was always in the little circle of red chairs with the others who were slow learners or "dummies," as the other kids called us. I tried so hard, but could learn so little.

Some of the teachers would embarrass me in front of the class when I would go up to ask for help. I remember my seventh grade math teacher. I had made up my mind that I would watch every move she made in explaining the math problems for the day, and when she had finished I did the first problem and it was right. But when I tried to repeat the process I could not remember how it was done. It was as though someone had reached up and pulled a blank shade down, shutting out the answer to the problem and all thought leading up to it. When I went up to the teacher for help, I was told to take my seat, and was accused of not listening (because I was always the first one up to her desk after she had just explained the problem). After awhile I found that I learn best auditorially, and that if someone would read the test questions to me, I could answer the

Generations, continued on page 22

From the Editors

This issue of IMPACT focuses on the empowerment of families with a member who has a developmental disability. In its pages, professionals share strategies and models for a collaborative, respectful approach to service provision. Families also share their experiences in seeking support and assistance from systems that all too often undermine human dignity and family integrity.

Our human service delivery systems have developed in ways that often respond to the "broken parts" of persons with disabilities, rather than seeing the needs and capacities of the whole individual in the context of his or her family. The new emerging model of service provision encourages service recipients to control the process. It views individuals with disabilities and their families as the true experts on their capabilities and needs.

We hope that this issue of IMPACT will encourage service providers to further explore empowering approaches to working with persons with disabilities and their families. We also hope that parents and other family members will read the stories in these pages and realize that many families share similar experiences and are finding options for obtaining services in a manner that allows them to decide their own fate.

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Decision Making in the 90s: A New Paradigm for Family, Professional, and Consumer Roles

by Jean Ann Summers

For every child or adult with a disability who is receiving social, medical, or educational services from the "system," the question that must be asked first is, "How shall we decide what services the person should get?" As recently as 10 years ago, we thought we had that question answered and the roles of all the key players clearly defined. First, the professional team conducted assessments and then met in some kind of individualized-plan team meeting where each team member presented results of his or her assessment and recommendations for what should be done. Second, the family (meaning the parents) was there to guard the legal rights of the person and to try and assure that the human being was somehow not lost as the professionals each focused on separate pieces of that person. And third, the consumer ... well, the consumer was supposed to show up and be happy that all these people were interested in doing "what's best" for him or her.

Now, however, we are talking about changing all that. The new concepts have been variously termed "family-centered services," "person-centered services," "family empowerment," "consumer empowerment," "family-driven assessments," and "self-determination." The main assumptions of the new concepts are that people with disabilities are capable of determining their own fates, that they and their families should be empowered to develop their own resources rather than becoming dependent on the system, and that they should be, in essence, in the driver's seat when it comes to deciding what services and supports they need. In fact, the idea of family- or person-centered service planning represents such a change from the former way of doing things that it has been hailed as a new paradigm.

■ The New Paradigm

The vision of the new paradigm is a heady one: We see professionals empowering families to empower their members with disabilities to live fulfilling and complete lives in the community. However, paradigm shifts are like earthquakes. Once a quake is over, we can adjust to, and even enjoy, the new terrain. But while everything is in motion, we can be pretty uncomfortable. Similarly, there are numerous questions, uncertainties, and even anxieties being voiced by everyone on the decision making team who wants to embrace the family-centered paradigm. It looks great over on the other side, but while the paradigm is shifting, everybody is on shaky footing. The questions raised during the paradigm shift are deceptively simple: If the family and/or person are supposed to be in charge, then what, precisely, is the role of the professionals on the team? Similarly, if a person with a disability is supposed to grow up to take charge of their own life and live independently in the community, then what is the role of the family, and how does it change over time?

People with disabilities, like everyone else, go through a series of life stages. So, too, do families as their members grow, develop, and age. At each life stage the needs and developmental tasks of both individuals and their families are different. Service systems have been roughly arranged around those life stages: early childhood, school years, adulthood, and aging. Within each of those stages it may be possible to define the roles of professionals, families, and people with disabilities with respect to decision making. To do that, however, will require laying two broad ground rules to govern our thinking about roles at each specific stage:

- The family's role in decision making with respect to a child or adult with a disability can be defined by considering the family's role with respect to any child or adult at that particular life stage.
- The role of programs and professionals is to provide support to help the family and person with a disability to come as close as possible to the roles and supporting relationships they would assume with any family member.

■ New Roles in Early Childhood

Parents or other adult caregivers have nearly total control over the lives of infants and toddlers. As toddlers grow they begin to assert their own choices; the "terrible twos" represent the first of many transitions children may make as they struggle to develop their autonomy and separate identities from their parents. The family's job, meanwhile, is to provide a sheltering ring or circle within which the budding little personality can develop without the threat of harm from the outside world.

Many parents of infants or toddlers with disabilities describe their first reaction to the news about their child's disability as a sense of loss of control over their child and family. Sometimes this loss of control is intensified by an army of professionals rushing in to address the child's health, social, and educational needs. In other words, professionals and service programs may seem to be invading the sheltering circle rather than assisting the family in creating one. The job of those filling parenting roles in those early years is to learn how to reestablish control and to rebuild that circle with the help, rather than the hindrance, of the professionals.

For professionals, it is important to realize that the role of early intervention for families is the same as the role of early intervention for young children: to foster growth and build a solid foundation for the future. Parents may have no prior knowledge about their child's disability, and their introduction to this world of services and programs is often abrupt and rude. Therefore, it is important to help them build skills to enable them to stand up to the lifelong task of caring for a member with a disability. This means helping them learn the ropes of the system, how to problem solve and make decisions, how to negotiate, and above all, learn that they are experts on their child and have the right to be recognized as such. These are the skills that can help parents become effective decision makers not only during the early childhood years, but also into the future.

■ New Roles in the School Years

During school years, and especially on into adolescence, the family's job (done imperfectly by most of us!) is to gradually loosen the bounds of the circle. Children venture forth to school and to their peer groups, but the family continues to be the safe harbor. Those in the parenting role continue to be responsible for major decisions, but at the same time may begin to draw the youngster into the process. Allowances, family conferences to make decisions about such things as vacation plans, and dinner table discussions, are some of the many ways adults may use to teach children responsible decision making.

For the family of a school-aged child with a disability, decision making may focus on the child's individualized

Paradigm, continued on page 20

Family: What are Our Assumptions?

by Mary F. Sinclair

What is family? When you think of parents, who do you think of? A husband, wife, and their children? How about a grandmother and grandchildren? Or an uncle raising his niece and nephew? How about a lesbian couple and their child? Families take many forms. A single image or definition of family or parent, as in the "nuclear family," is potentially detrimental and devaluing to those who fall outside of the definitional parameters.

One's images of family or parent influence one's ability to interact with a family in an empowering manner. Consider for a moment defining "family members" or "family leaders" by the individuals who fulfill those roles rather than by their biological or legal relationships. Would this definition be more reflective of the actual nature of many families? How would use of this definition affect the way services are provided? Would it recognize and empower a greater number of families?

In 1989, California assembled the Joint Select Task Force on the Changing Family to plan for a comprehensive statewide family policy. The task force concluded that the family *role and function* in society is a more inclusive common denominator than family *structure*. The task force identified the family as the primary social and economic unit whose functions include: (1) maintaining the physical health and safety of family members by providing for basic necessities; (2) providing conditions for emotional growth, motivation, and self-esteem within the context of love and security; (3) helping to shape a belief system from which goals and values are derived, and encouraging shared responsibility for family and community; (4) teaching social skills and critical thinking, promoting life-long education, and providing guidance in responding to culture and society; and (5) creating a place for recreation and recuperation from external stress.

It is ironic that our human services delivery system typically does not operate in a way that builds capacity in families. The task force report indicates that policies intended to support families in a way that will enable them to fulfill those basic functions must:

- Consider an inclusive definition of family.
- Recognize the family's inherent strengths and enhance, rather than replace, family resources.
- Recognize that the family is part of a community, and that strengthening the community can strengthen families.
- Broaden the options available to families, enabling them to make choices that are responsive to their diverse situations and their own special needs.

It is my belief that policies and programs guided by these themes of inclusion, strength, community and choice truly serve and empower families.

Reference:
Novick, S., Walsh, J., Zimmerman, E. (1989). Planning a family policy for California: First year report of the joint select task force on the changing family. Sacramento: Joint Publications Office.

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Access to Services: Sharing the Power

by Fran Smith

Thirty-seven years ago, during our monthly visit to the Well-Baby Clinic sponsored by our county health department, I asked the doctor why my eight-month old baby didn't hold up her head and why her arm motions were "different." The doctor took another look and said, "This baby has cerebral damage, obvious cerebral damage. She probably has cerebral palsy." If she said anything else, I didn't hear her. I'm sure I nodded my head as I quickly dressed Cheryl and ran outside to where my mother was waiting to take us home. The dreaded words, "cerebral palsy," kept repeating in my head, over and over and louder and louder. I couldn't answer my mother's questions because I was crying so hard.

The weekend was a blur of gazing at my beautiful first-born, knowing that her life would be empty and lonely, that other children would tease her, that none of the dreams that I had for her would ever come true, and that our future would be endlessly bleak. By Sunday night, even though I couldn't find an answer to "Why me?", I was resolved to be the best parent she could have.

On Monday morning our public health nurse was at my door. She apologized for not offering more assistance during the clinic visit, and she brought me a book on cerebral palsy, pamphlets on therapy, and the name and meeting time of the Cerebral Palsy Society in my town. She sat with me for over an hour answering the few questions I had and offering encouragement and support. As I look back I realize that she gave me hope, information, and direction exactly when I needed it. Cheryl and I were on our way.

Through the years, both as "just a parent," and later as a professional in the field, I have talked with several hundred parents, sometimes as their advocate and more recently as a workshop leader. Every parent I've talked with has the same commitment to doing what is best for their child. This could mean knowing everything there is to know about the condition, finding the right doctor, obtaining the best service, or fighting a denial of funding or service. The comments I still hear are:

- We need information about services.
- Why do we have to make 14 calls to find one service?
- Why are eligibility requirements different for every service and why do we have to fill out a different form for each service?
- Why don't professionals know the information we need?
- Why can't services be more user friendly?

We've come a long way in 37 years, creating billions of dollars of services and millions of slots for professionals, but parents still can't always find what they need. And worse, many times when they do find what they need they are frustrated when they try to "get in the door." Parents still tell me that their best source of information is other parents.

In the best of all worlds, at the moment of diagnosis, parents would receive a how-to manual on everything they should know about the condition, the services their child will need and where to find them, all the laws pertaining to their child, and how to be an effective spokesperson for their child when services are not readily forthcoming. In this utopia, parents will be told about support groups, parent training programs, and other services. Everything the child needs will be available at the exact time they need it, and parents will be accepted as equal partners in the planning process for their programs. All the services will be adequately funded and all the professionals who provide them will share similar values and love the child and appreciate their uniqueness as much as the parents do. Parents will never have to speak out except to say, "Thank you."

Until then, perhaps a few guidelines will help both parents and professionals:

- Parents may find it helpful to start their search with the yellow pages, the public library, the United Way office, and of course the most obvious, the agency using the name of the condition.
- Parents can ask directory assistance if there is an 800 number for a service or condition.
- Service agencies can employ a parent to take information and referral calls.
- Directors of service agencies should try to find their agency in the telephone book and/or try to enter the service as "just a parent."
- Personnel who give information over the telephone, or handle entry visits, should give themselves an attitude test to see if they'd like to be on the other side of the phone or desk. Remember, people could be coming to you at their darkest hour.

Some innovative routes to services are being developed. In some states, the Developmental Disability Council, the Parent Training and Information Center, and/or the Protection and Advocacy agency have installed an 800 number. Many hospitals include information about parent support groups as part of the discharge package for an infant. In a city near me in California, a local hospital has created a data bank on services for children with complex medical needs and parents can access the information through their home

computers or through that of any one of several local agencies. In New England, a consortium of hospitals has installed a similar service. In some states, early intervention programs, special education, and the mental retardation/ developmental disabilities agency are talking about utilizing the same eligibility criteria and developing a single entry form. This list is a starter and should continue.

In my vision of a perfect world, five years from now the disability field will have combined the smarts of TRW and the technology of the automated teller machines with the information needed by parents so that 24 hours a day we can use walk-up windows to find out about services. I talk about this vision everywhere I go and most people laugh. But one mother told me she wouldn't be satisfied unless the respite worker came out of the slot. That may take more than five years.

My parting thought is this: Information is still power, power to change lives and make brighter futures. If you need it, keep seeking until you find it. If you have information, put it forward in the most user friendly ways possible.

Fran Smith is an independent consultant specializing in empowerment and family support. She lives in Richmond, California.

Sara Pearson: "I'm finer than frog's hair; the illness isn't doing so well."

A Parent's Quest for Credibility

by Jean Pearson

". . . if you are convinced that the mother has the child's best interests at heart, then I think it would be appropriate for her to make whatever treatment or nontreatment decisions she feels appropriate considering the overall condition of her child, whom, it seems to me, she clearly loves and has cared for all these years.

- correspondence to my daughter's attending physician from Ronald E. Cranford, M.D. , neurologist and bioethicist

A constant challenge I face in being an effective case manager on behalf of my daughter, Sara, is establishing my credibility as a mother who truly loves and cares, a mother who has her daughter's best interests at heart. Adjectives with which some professionals have labeled me include, "bitchy," "hysterical," and "overly-demanding." Yet, as Dr. Cranford states, because my credibility is valid, I am the decision maker.

Consider the following, also from Dr. Cranford's letter: "Even though Sara is severely demented, nevertheless, as much as possible any feelings she has towards treatment...should be considered in any decision making process." As the decision maker I have chosen to allow Sara to participate, as she is able, in making decisions that affect her living/dying. Having made this choice I am, at times, put in a catch-22: some medical professionals want to hear Sara's choices yet, once expressed, they inform me that her choices are not valid. Challenging that premise, I risk being described by some through use of the previously listed adjectives.

Another list of descriptors from other professionals, Sara, and myself - the list I choose - identifies me as compassionate, sincere, beautiful, intense, tenacious, wise, and ever-evolving. (Thank you Sara for the numerous times you have told me I am beautiful). I reflect on this list and see its intimacy with my credibility, my often times hard-earned credibility, as a mother engaged in learning how to "take Fate by the throat and shake a living out of her" (Louisa May Alcott).

I bring to this experience, as each of us does, my own story, a story including both failures and successes in believing myself to be credible. For those of you who share this journey with Sara and me, I ask that you not define me as the mother of a daughter with a chronic, degenerative illness. Rather, see me as a vital participant in a set of circumstances that has the potential to both bless and curse; not demanding answers, but seeking to live fully into the questions, thereby enhancing my humanity as woman and mother.

Help me in this situation to continue to believe in myself and in each of you. I want to trust that together we may gift Sara, my daughter, with the most meaningful life possible, thus enabling the truth of Sara's eloquently spoken, sincere words to endure: "I'm finer than frog's hair; the illness isn't doing so well."

Jean Pearson, Sara's mother, is currently working on her Master of Arts in Liberal Studies at Hamline University. She is employed as an Advocacy Caseworker for the Minnesota Alliance for Health Care Consumers.

The Impact of Personal Futures Planning on Families

by Angela Novak Amado

Personal Futures Planning is an individualized, structured, possibility-based approach to life planning. The individual plan represents a vision for a more desirable future, developed by a group of people who care about the individual and are willing to assist in making the plan become a reality.

The process starts with a focus person, a group of people who care about the focus person, and a group facilitator. Large sheets of paper on the wall are covered with colorful pictures and statements. The first meeting, a Personal Profile, looks at a person's history, relationships, strengths, and gifts. In the second meeting, the group develops a dream or vision for a desirable future. People make commitments to certain actions to help bring the dream into reality. Then, the group continues to come together to share successes and failures and to continue to move forward.

Personal Futures Planning was developed by Beth Mount and John O'Brien, and has been used for more than 10 years in many different states. It can be used with any person of any age. It is often used to discover what's possible for people when looking from the perspective of the person's capacities rather than the traditional deficit-based planning approach, and to empower people who care. Persons with disabilities, service providers, case managers, and families, have all reported being profoundly impacted by the process. They can see people in new ways, understand people much differently, and be more inspired to realize much different dreams and visions for the person than what occurs in traditional planning processes.

The Minnesota Governor's Planning Council on Developmental Disabilities has sponsored three years of training in Minnesota on Personal Futures Planning. More than 200 people have received plans in those years, and many families have also been impacted. Some examples of the kind of differences the process makes for families and for individuals with disabilities are the following:

- **Transitions**. Personal Futures Planning is often used at different transition points, such as from early childhood to regular school programs and from school to adult services. It is also used for transition to new services, such as group home to apartment living and sheltered to supported employment. One example of using Futures Planning for transitions is Emily's parents and early childhood staff, who used the process to discover that it was possible for her to go to regular kindergarten. At the planning meeting, Emily's mother said: "We had hopes for her. But we never told people those hopes because we didn't think they could happen." Emily now attends kindergarten in a district that has never before served children with her severity of disability in regular kindergarten.
- **Services**. The Futures Planning process can often help clarify what the best situations for people could be. For example, Gary's family could not care for both Gary and his sister at home, and his mother would not hear of him moving to a group home. The planning group helped find a foster couple who lived near Gary's family and went to the same church. Gary's mother is now able to feel good about him living away from home.
- **How the Person is Seen**. In the Futures Planning groups, families and other group members often come to see the person in new ways, such as viewing them as more like other people and more capable. For example, a woman who had been living in a locked unit at a regional treatment center was thought to be helpless or dangerous; however, when she was pouring coffee and socializing at her planning meeting, family and other group members had their anxieties eased. They helped her move out of the center and back to her hometown.
- **Empowerment**. Through Personal Futures Planning, families can be empowered in obtaining support and in facing sometimes scary decisions and futures. For instance, Gordon's mother was empowered to move from just complaining to writing and getting others to write letters requesting more respite care.
- **Being Involved**. Often, the Futures Planning process has enabled family members to become involved again. The focus is on capacity and gifts, and the real interest is in a person as a human being, not just a "client" or "special education student". Through the process, group members often get excited about inviting family back into people's lives. For example, Pat's family members have been amazed to discover that the person they thought was "a vegetable" is very capable, and have been thrilled to reconnect with him as part of their family.

Personal Futures Planning as a process has brought people together who have traditionally been adversarial or focused on the service system. It has allowed them to see and care about others as real human beings. Through the process many individuals with disabilities and their families have been able to express wishes and dreams, and to have those dreams come true.

Angela Novak Amado is the Executive Director of the Human Services Research and Development Center, 357 Oneida Street, St. Paul, MN 55102. For further information on Personal Futures Planning contact the center, or see the Resource list on page 19 of IMPACT.

Advocacy: Noun, Verb, Adjective or Profanity?

by Linda Gress Bonney and Sandy Moore

Depending on your perspective and your personal experiences, advocacy can be exciting, challenging, frustrating, frightening, or a relief. Advocacy is often misunderstood. Yet, all of us at one time or another have found ourselves acting as an advocate for our children, our students, our friends, or ourselves.

For the purposes of this article, advocacy is defined as information, advice, and representation provided to individuals and their families to assist them to acquire appropriate services for a person with a disability. An advocate is a person trained to provide support, advice, and legal representation to children and adults with disabilities.

Law, regulation, and policy set out a process and procedural safeguards within each service system for persons with disabilities. This is true of social services, education, and the health care systems. The process of accessing any service includes at minimum, application, eligibility, assessment, service plan, service delivery, and delineation of financial responsibilities. When this process is working well, there is no need for an advocate. When there is conflict or disagreement in accessing or providing services, then an advocate might be called. The primary purpose of an advocate's involvement is to resolve conflict. The advocate's role is to serve as a "guardian of the process" to ensure that the required steps are taken to identify and meet the needs of the people that each system is mandated to serve.

Families are frequently referred to an advocate by other families or professionals who recognize that the process has been derailed and that an outside party will be needed to get it back on track. Often, persons request the assistance of an advocate as a last resort. Many have been threatened with discontinuation or reduction of services. Some of these people will have attended many meetings, without results, while others were unaware of their right to convene a meeting at all. Some will have patiently identified and repeated the problem over and over as they've been passed from one agency to the next, while others may not have found even one person willing to listen or to help.

At this point, families and professionals are often feeling angry and frustrated. Family members may be reluctant to involve an advocate, not wanting to be seen as troublemakers and being fearful of possible retribution to their family member with a disability. Professionals may be feeling defensive. People with disabilities, their families, and friends need to realize that they may be in that painful position of choosing between "not rocking the boat" and getting what is needed for the person with a disability.

It is not the role of an advocate to dictate the outcome, but rather to direct the process in order to reach the desired outcome, which is implementation of services designed to meet the unique needs of the person and family. The first step for the advocate is to gather the information necessary to identify the problem and determine where and how the process got derailed. The advocate will often be seen as a persistent person who asks and re-asks many questions regarding the details of what has taken place, the players involved, and the roles and power of these players. The advocate will need to look carefully at all of the relevant assessments and information to ensure that there is documentation supporting the professional recommendations and decisions that are being made. This is where the advocate's knowledge of the laws and regulations is critical in order to determine the appropriate strategies to employ.

The advocate's job is not to ensure that all participants are comfortable or happy, but to ensure that the person with a disability gets the needed services. Yet, a successful advocate will be an experienced problem solver, and will work to move the team towards resolution in a focused, positive manner. A skillful advocate will always be cognizant of the fact that their presence is temporary, while the person with a disability and family will be in the position of working with many of these service providers on an ongoing, long-term basis.

While working through specific issues the advocate has a responsibility to help build others' confidence and skills so that all of the people involved will be better equipped to deal with problems in the future. In addition, the advocate attempts to build the supports necessary for the individual and family to continue to informally advocate for themselves, and for them to know and follow the processes that ensure provision of services throughout life.

There are several things that persons with disabilities and family members can do to more effectively use advocacy. First, they can learn as much as possible about the program(s) they are working with, and, before problems arise, ask for written information on their rights and the appeal process for each program. Also, they can identify which professionals are responsible for assisting with which types of problems. Secondly, as problems arise, it's important that individuals and families identify what they want and/or don't want in services before contacting an advocate. And finally, it's better to request assistance before doom appears inevitable. We have yet to meet an advocate with wings, and there is seldom a magic answer that offers a "quick fix" to longstanding problems.

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Self-Determination and Empowerment: The Parent Case Management Program

by Marijo McBride

In the past, the management of services for persons with developmental disabilities was largely left to professionals. Individuals with disabilities and their families followed the lead of "experts." Today, more families and persons with disabilities want to be involved in determining their own needs, desires, goals, and supports. There is growing recognition that each person with a disability and his or her family are the true experts on their situation.

There are several problems that commonly arise in connecting families with appropriate services. According to one study, many families don't know what services are available to them and what their legal rights are in regard to receiving specific services. In addition, many families don't have the skills to advocate for their member with a disability to ensure that they receive the appropriate services. (Zirpoli, Wieck, & McBride, 1989). The Parent Case Management Program at the University of Minnesota is addressing these problems. The program is providing tools to assist persons with disabilities and their families to take active roles in determining the services and resources they need and the way those services and resources are delivered.

> Today, more and more families and persons with disabilities want to be involved in determining their own needs, desires, goals, and supports.

The program is committed to building on the unique capacities of each family and enhancing its active participation in determining its own needs and directions. Participants in the program receive training, support, and consultation in the following areas:

- Case management procedures, responsibilities, strategies.
- Civil rights of persons with developmental disabilities.
- Data privacy.
- State-of-the-art service delivery and philosophy.
- Quality indicators in health care and other services.
- Transition planning and implementation.
- The importance of being a part of the community.
- Technology.
- Case management rules and regulations.

In addition, participants develop the skills needed to be effective case managers for themselves or their children with developmental disabilities, including skills in effective use of resources; maintenance of appropriate records; conducting effective meetings; and identification of needs, goals, services, and resources.

The program is based upon the understanding that families who have a child with developmental disabilities are significant members, if not the most important members, of any case management planning team. The program helps professionals to view families in a new way, and to challenge and invite families to be empowered and take charge.

The Parent Case Management Program, a joint effort of the university's Institute on Community Integration and the Minnesota Governor's Planning Council on Developmental Disabilities, has existed for five years and has conducted training sessions throughout Minnesota. This year, it has added a new component: the training of parents and other interested persons to serve as facilitators. With these additional trained personnel the program will be implemented in more areas of the state.

How effective is this approach to family empowerment? Evaluations of the program reveal that, following training, participants significantly improved in their ability to assess their own or their child's strengths, progress, and specific needs, and to make a plan for service. Case managers of participants report that the participants requested more or different services after training than before training; in addition, the training improved the working relationships between case managers and families. Participants reported that the training improved their self-empowerment, links with social networks, knowledge about rules and regulations regarding services, and competence in accessing services. These evaluation results indicate that this project is beneficial, and that it may be an effective alternative to the current case management systems in many states.

Reference:
Zirpoli, T.J., Wieck, C., McBride, M. (1989). Case management: A new challenge for families. In M.H. Linz, P. McAnally, and Wieck, C. (Eds), Case management: Historical, current and future perspectives (p 127). Cambridge, MA: Brookline Books.

Marijo McBride is Coordinator of the Parent Case Management Program. For further information contact her at the program, University of Minnesota, Institute on Community Integration, 103 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 624-6830.

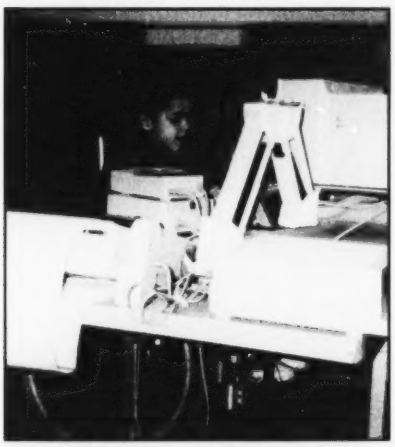
Empowering Rural Families: Two Success Stories

These two stories illustrate some of the issues for families in rural areas who have a member with a disability. Through the Parent Case Management Program (see opposite page) both of the families in these stories found hope and help.

■ Making Connections

Our family comes from a small northern Minnesota town. My wife, Dianne, and I have two children: Zachary, 7, and Kadie, 4. Zach has cerebral palsy, and obtaining services for him has proven to be an ongoing challenge, a challenge familiar to most who share our "outstate" status.

Finding out about and getting services for Zach has often been confusing and frustrating. Although we have been lucky to have a good medical program for physical and occupational therapy, there have been many areas where services were underaddressed, if they were addressed at all. We received mailers about forums offered by different organizations, and usually tried to attend. This would most likely involve a lengthy drive, and sometimes wasn't worth it because we didn't really have a good idea of which ones would best suit our needs. We made initial contact with the county agency that handles case management in our area, but nothing developed. Zach was enrolled in an early childhood program provided by a neighboring school district; the program was good and he thrived there, although the facility, a partially renovated airbase, was substandard. He now attends school in his neighborhood district and does well, though some of his needs are compromised because there are not enough qualified people to fill the therapy positions.



Zach Johnson at the classroom workstation his father designed for him.

The Parent Case Management Program was a major turning point in successfully obtaining services for Zach. We attended the training and became equipped with the tools necessary to be more effective advocates. We took the first step by getting a case manager assigned to Zach. Together, we worked on and learned about the services that Zach would qualify for. We made numerous applications; some were successful and some weren't. The point is, we were finally able to get the information that was right for us.

Raising a child with a disability in a rural setting presents its own set of challenges. However, if parents, professionals, agencies, and organizations can consistently work together, it should make everyone's work easier and more effective.

The Johnson family lives in Grand Rapids, Minnesota.

■ Reclaiming the Future

Our youngest daughter's sixteenth birthday was a flurry of excitement. In addition to receiving her driver's license, Marta began her first summer job, clearing tables at a resort restaurant.

Marta, in her 1992 high school graduation photo.

Our hopes for her future--graduation and college--came to an abrupt halt on July 9, 1987. While driving home from work late that night, she lost control of her car on a curve and collided with a power pole. She sustained a traumatic brain injury and was airlifted to a hospital in Sioux Falls, South Dakota, where she was placed on total life support. She remained in a coma for one year and was semi-comatose for a second year. When we brought her home in 1989, we faced decisions never faced before in our small community. My husband and I felt especially alone.

After enrolling Marta in our school's special education program, we began attending workshops on educational rights and transition issues. While we had these resources, no one seemed able to explain the "big picture" in planning a meaningful future for Marta.

In 1990, I enrolled in the Parent Case Management Program. I met many other parents from our region who had similar frustrations in their isolated communities and didn't know where to turn for help. Through the training, I became familiar with the concept of empowerment, the true spirit of advocacy, and Marta's rights in her school and community.

We have now learned to ask the right questions of the right people in service-providing agencies. Armed with determination and supportive materials, we are convinced that Marta will not be sidelined in life. We are no longer alone. As our daughter continues to improve day by day, we once more are confident about her future.

The Achterhof family lives in Luverne, Minnesota.

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Making the System Work: The Multicultural Family Inclusion Project

by Jamie Smith

Information, understanding, support, and empowerment: The Multicultural Family Inclusion Project is trying to deliver all four to African American parents of children with disabilities. The project - a program of PACER Center in Minneapolis - provides African American parents with a network of peers who are advocating on behalf of their children with disabilities, advocating in a system that traditionally they haven't trusted.

> It is an intimidating process....Everyone in the room talks about and makes decisions about my kid like I'm not even in the room, and they put the piece of paper in front of me to sign. Often, this doesn't work.
>
> ***- Father of a child with a disability***

"We want parents to know that they are not alone," states Beverly Price, coordinator of the project and mother of a 23-year-old daughter with a disability. "We affirm the knowledge African American parents have about the needs of their families. The information and skill building that we provide empowers the parents as they advocate for their sons or daughters."

Twenty to thirty parents participate in the project. The hope is to improve their understanding of disabilities, increase their confidence in advocating for services for their children, and to make them aware of resources that are available for their sons or daughters. PACER has established support groups for African American fathers, parents, parents of children with autism, and siblings. "They're helping each other and providing support for one another," Price says of the members. "One mother has been like a sponge, soaking up all the information on laws and resources. She wants to know what other services are available and how she can help other families." Support group topics have included:

- Parents' experiences with their child's assessment, led by a clinical psychologist.
- Building self-esteem in African American children.
- Understanding a child's Individual Education Plan or Individual Family Service Plan.
- Educational rights of children with disabilities.
- Medical issues.
- Resources for children with special needs.
- Attitudes toward disabilities that exist in the African American community.

"I feel that some African American families don't talk about their children with disabilities. As a result, they aren't aware of information or resources that would be helpful," Price says. "We want families to feel comfortable discussing their child's disability, to be aware of resources and the needs of their children, and to feel confident that they can talk with other people. Traditionally, we have not trusted that the systems would serve our families well. We have to learn to be assertive and communicate with professionals so our families will receive services that will be respectful and sensitive to our needs," she concludes.

The five-year project began in October 1989, and is supported through funding from the University of Minnesota's Center for Children with Chronic Illness and Disability. In the first year, PACER focused on establishing the support groups for parents and siblings, and providing individual assistance to families. Price has introduced the project to African American groups within the Twin Cities. PACER also is completing a new videotape that describes, through personal interviews, the experiences of African American families who have children with disabilities (*see resource list on page 19*). PACER is beginning to expand the multicultural project to include the Southeast Asian and Hmong communities, for which it will establish similar support groups and also produce a videotape. Through these efforts, PACER hopes that families will begin to trust that they can make the system work for them.

> I didn't realize there were so many other people out there like me and that if I talk and listen to other people, I can find other vehicles to help get things my son needs.
>
> ***- Mother of a son with disabilities***

Jamie Smith is Administrative Assistant at PACER. For more information about the Multicultural Family Inclusion Project contact Beverly Price at PACER, 4826 Chicago Ave. South, Minneapolis, MN 55417-1098, (612) 827-2966 (voice/TDD), (800) 53-PACER (toll free for parents in greater Minnesota).

Note: Pictured in the cover photo are (L to R) Karla Scott, Patricia Kimbrough, Carlean King, and Beverly Price.

Family Mediation as Family Empowerment

by Patricia A. Moses

Hennepin County Juvenile Court receives an average of 1200 referrals for truancy each school year. The schools allege that each of these children has missed at least 10 and up to 40 or more days of school without a lawful excuse. The court knows that children who are truant are at high risk to commit delinquencies, abuse chemicals, and generally to experience academic, social, and emotional problems.

The stereotypical image of the school boy playing hooky so he can go fishing is from another era and virtually nonexistent in the population of youngsters who are sent to court for truancy today. Today, truant children face sometimes overwhelming obstacles to their healthy development; the truancy is a symptom, a red flag. Schools hope that the court will enforce the law requiring school attendance, and "fix" the child so that he or she will not be truant again. Both goals have been elusive for many reasons, including an unrealistic perception of the extent of the court's authority and a lack of resources to carry out the court's orders.

A couple of years ago, the Hennepin County Juvenile Court requested assistance from community agencies in providing services to truants. In response, the Minnesota Citizen's Council received funding for family mediation with truant children and their families. The council correctly surmised that many children who are truant are also experiencing family problems that interfere with school attendance. Family mediation is used as a diversion from court. The family is offered mediation with subsequent dismissal if the child completes mediation and returns to school regularly.

Because it is voluntary, participation in mediation is not in response to a court order, but in response to the child and family's own perceived need for change and wish for the child to return to school. Because the mediator is neutral, issues can be more readily identified and accepted by the participants. Often, school- or education-based problems are identified and the school itself becomes a party to the mediation. Mediation is realistic and makes sense to families. There is no pretense of therapy. While therapy may also be indicated, mediation is a direct approach to dealing with specific obstacles to a child's school attendance. Even families who seem to have longstanding and quite serious problems have been willing to work towards positive change. And when change happens, the child experiences success at school and in the home, without the boot of the court behind him or her.

By nature, the court is the institution in our society with ultimate power over persons who come before it. Mediation tips the balance of power in a sense, as it encourages families to learn lifelong dispute resolution skills that help them to avoid court now and in the future. Many of these families have ongoing contact with institutions. The skills learned in mediation are adaptable and continue to empower families in other contexts.

From the court's perspective, the child and family are empowered when they are able to successfully address a problem such as truancy and at the same time "beat the system," here, the two institutions of school and court.

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Successful Mediation: Families Learn to Communicate

by John Conbere

As mediators, we see many adolescents getting extremely frustrated and, not knowing how to end the conflict, they stop going to school, or run away from home, or commit a crime within the family (such as stealing the family car, or assaulting the parent). In mediation, our goals are to end the conflict so that the adolescent will no longer need to act out, and also to model a means for resolving conflict in a "win-win" fashion that families can use after mediation concludes.

We have found that both parents and children want to have reasonable needs met. Usually they are not being met because no one has shown the parent and child how to do whatever is not being done. For instance, in one family the child was adamant about wanting her father to show that he cared about her. He yelled at her and she felt unloved. Her parents wanted her to succeed in school and to do her share of the household chores. Many other issues were raised in the six hour long mediation sessions, but these were the heart of the problem. In the discussion it turned out that in the father's own childhood he had not been shown love, and he did not know how to show his daughter he loved her. He said he loved his daughter, and added it was scary to deal with his inability to show his feelings. He wept a bit as he acknowledged this. By the end of mediation, the daughter was back in school and doing more chores. Her parents were pleased with her progress. Her father was trying to express his frustrations in appropriate ways. An impasse was reached about showing his love. She had heard how hard

Mediation, continued on page 23

Home-School Collaboration: A Building Block of Empowerment

by Mary F. Sinclair and Sandra L. Christenson

The meeting was held in the basement of a local public library. We were bringing together, for the first time, the committee members of our dropout prevention advisory group targeting middle school youth with learning and behavioral disabilities. The committee was and is comprised of individuals who interact directly with youth, including parents or other family members of children receiving special education services, educators, community organization youth advocates, and the youth themselves. The first discussion began with parents blaming "culturally insensitive teachers," teachers blaming "unresponsive and uninvolved parents," and community agency folks blaming "everyone."

It is relevant to mention that the initial task of the committee was to identify the reasons why students stay in school or drop out of school, and to propose programs and broad changes that encourage youth to remain in school. Needless to say, everyone took the opportunity to express their feelings and frustrations. Fortunately, one of the advisory committee members was a trained mediator and was able to sincerely acknowledge everyone's deeply felt concerns and yet at the same time remind us all that these concerns were exactly the reason why we were all gathered around the table. Throughout the subsequent meetings, the committee members were more concerned about the complexity of the problem, and more cognizant of the commitment of all the key stakeholders, than they were concerned about assigning blame.

As we -- staff of the Partnership for School Success project - continue to facilitate bringing educators, families, and other youth advocates together, this developmental process of ventilating frustration, blaming others, and then moving beyond blame to collaborative problem-solving has been repeated consistently. We have almost come to expect the process to happen, and therefore make a concerted effort not to let it bring our initiatives to a grinding halt. We are continually reminded that no one individual constituency in isolation can prevent youth from dropping out of school or resolve other school-related problems experienced by youth with disabilities. Only when we work in partnership with others are we empowered enough to provide a successful learning experience for all students.

■ The Importance of Collaboration

Collaboration is an attitude, not an activity, and is integral to the educational success of students. Why a shared responsibility among home and school for promoting positive academic and socialization outcomes? The theoretical underpinnings of a partnership approach for improving student learning include at least three points:

- Only through collaboration can we all become empowered to make change. Given current economic and societal conditions, schools alone cannot meet all children's needs. The sheer number of at-risk children, problem situations, and changing demographics of American society dictate a collaborative stance.
- Children learn, grow, and develop both at home and at school. There is not a clear cut boundary between home and school experiences for children and youth. Rather, there is a mutually influencing quality between experiences in these two settings.
- A learning environment is educative when it enables the individual to learn and develop specialized skills; it is miseducative when it fails to encourage positive human development. The educative community is produced when learning environments of the home and school are linked together and carefully coordinated to serve the developmental needs of individuals.

■ Effects of Family Involvement

One outcome of effective home-school collaboration is increased meaningful family involvement in education. The family members typically involved are the ones fulfilling the parental role.* Research indicates that students' academic and socialization outcomes are higher when parents are meaningfully involved and programs are comprehensive. Student learning is enhanced when there is a match between the efforts of home and school. Furthermore, there is also evidence that discontinuities between family and school have a negative effect on student learning.

It is important to clarify, however, that involvement of family in education is not about shifting educational responsibilities from the school to home. Parent involvement is seen as an additive if not synergistic effect, and home-school collaboration is the goal. Educators and the general public need to "be realistic in [their] expectations for parent involvement as part of effective programs. Parent involvement as well as other forms of home-school collaboration can help, not cure, the problems of weak school programs, of children who miss opportunities, and families who feel confused about their children and the school" (Epstein, 1988, p. 59). Most studies, however, have focused on the individual or isolated influences of family on student achievement, which often leads to blame when a child is not achieving. Nonetheless, the following conclusions about the effects of parent involvement in education can be made based on four comprehensive literature reviews:

- All forms of parent involvement strategies seem to be useful; however, those that are meaningful, well planned, comprehensive, and long lasting offer more options for parents to be involved, and appear to be more effective. Student achievement is greater with meaningful and high levels of involvement.
- Parent involvement affects noncognitive behavior: Student attendance, attitudes about school, maturation, self concept, and behavior improve when parents are involved.
- There are benefits for parents, teachers, communities, and schools when parents are involved. In general, there are more successful educational programs and effective schools.
- Student achievement gains are most significant and long-lasting when parent involvement is begun at an early age.

■ Respectful Family-Professional Interaction

The first step toward collaboration is communication. If the parent(s) and teachers do not know each other and have never meet, how can they begin to collaborate? Furthermore, the initial phases of communication are fundamentally about trust building. Too often, a precondition for communication from educators to parents is initiated by a negative perception of a child's performance. Subsequently the parents' interactions with schools are often antagonistic, while at the same time some researchers argue that teachers' and schools' efforts to involve parents are among the most important influences on parent participation. Teachers' beliefs about the importance of parent involvement, comfort level with parents, and ability to communicate with parents on an equal basis influence individual teacher practices. In a study of teachers characterized as "teachers who involve parents in education," common beliefs and practices were identified. These teachers described parents in positive terms, perceived parents as an asset that is a basic element of a child's education, and believed education was closely tied to the home; they consequently made efforts to have classroom activities fit with children's homes. Although all teachers in the study perceived time and effort as a "cost" of parent involvement, the teachers who involved parents indicated that the effort was a necessary and important part of their work.

These types of anecdotal interactions between teachers and parents have been systematically categorized into five key elements of effective and respectful parent-professional interaction (Vosler-Hunter, 1989):

- Mutual respect for skills and knowledge. Parents and teachers are encouraged to recognize that they have equal value and worth, and acknowledge each other's strengths and expertise.
- Honest and clear communication. Parents and professionals are asked to examine their biases and preconceptions about each other up front, which in turn should promote mutual understanding and action in a timely and productive manner.
- Two-way sharing of information. This is essential in that the extent and nature of information exchanged is important and warrants sensitivity and responsiveness.
- Mutually agreed upon goals. This element calls for a change of balance - a need to move away from the dominate professional role and a passive role for parents or other family members.
- Shared planning and decision-making. Joint decision-making is described as an essential affirmation of the active role of the parents and advocates. Parents need to be included in the planning processes, which often nullifies issues of resistance and noncompliance on the part of the family.

■ Conclusion

Collaboration is an attitude that can focus and blend the efforts of families and educators into a complimentary support system for youth. True collaboration fosters open communication, trust-building, and a pooling of resources that is necessary if we are to address challenging goals, such as dropout prevention and family empowerment. If we can begin to collaborate, then perhaps we can begin to experience educational success for all youth.

*** Note: The term "parent" as used in this article refers to the person(s) filling the parental role, not necessarily the legal or biological mother and/or father.**

Note: Excerpts taken from Christenson, S.L., Rounds, T. & Franklin, M.J. (in press). Home-school collaboration: Effects, issues, and opportunities. In Christenson, S.L. & Conoley, J.C., Home-school collaboration: Enhancing children's academic and social competence. Colesville, MD: National Association of School Psychologists.

References:

Epstein, J. (1988). How do we improve programs for parent involvement? Educational Horizons, 66, (2), 58-65.

Vosler-Hunter, R.W. (1989). Families and professionals working together: Issues and opportunities. Focal Point, 4 (1), 1-4.

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Home-School Collaboration Model: Project FISC

by Cheri Gilman

The current move toward family empowerment in provision of services to children with disabilities represents a shift in policy and practice that requires many professionals to redefine how they do their jobs. In early childhood special education, for instance, legislation has essentially mandated parent involvement in educational decisions. The way in which parent-professional interactions actually occur in fulfilling this mandate can vary considerably.

The Families Involved in School and Community Project (FISC), in St. Cloud, Minnesota, has developed a process that enables families to be more actively involved in planning, accessing, and evaluating services for their children. This family-centered process is grounded in three broad principles:

- The unique strengths of each family should be acknowledged and utilized in meeting its own needs as well as the needs of its child with a disability.
- Assessment should be based on an informal, nonintrusive process emphasizing open-ended conversations and the establishment of family-staff relationships. There should be less reliance on standardized instruments/procedures.
- The process should enable and empower families. Enabling families entails creating opportunities and means for them to apply their abilities and competencies to meet their needs and the needs of their children. Empowering suggests interacting with families in such a way that they maintain or acquire control over their family life and attribute positive changes that result from intervention to their own strengths, abilities, and actions.

FISC personnel have developed a model Individualized Family Service Plan (IFSP) process to meet the significant educational needs of young children with moderate to severe disabilities and to facilitate family involvement in educational planning. By using an individualized family systems approach with families who have children older than the traditional birth to two year old age range for which IFSPs are currently being developed, the project has provided a special contribution to the educational programming of children and youth with challenging needs. The family component of a traditional IFSP can be an added component to traditional IEPs (Individual Education Plans) that are already in use for children who are of school age. Providing increased support in a manner that recognizes families' unique individual needs also affirms the feasibility of collaborative family-school partnerships.

There are five primary steps in the family-centered planning process. It is important to note that the process is individualized, so all families will not progress through it in the same sequence. Thus, these steps are only a framework:

- Initial contact. The student's case manager makes contact with the family as early as possible in the school year to give family members an opportunity to explore and communicate their initial preferences for the type and frequency of ongoing contact with the school staff.
- Preassessment planning. The case manager visits with family members to gather information that may provide direction for subsequent child assessments; elicit family members' preferences for their roles in the process, their perspectives on the child's strengths and needs, and their priorities and resources; and discuss options for collaborative goal-setting during the IEP conference.
- Child assessment. Classroom teachers and consultative staff contribute discipline-specific assessment expertise relating to child strengths and needs and the priority areas identified by the family.
- Collaborative goal-setting at the IEP conference. The initial or annual IEP conference is conducted to identify child goals, instructional objectives, and criteria for success. Annual goal statements reflect the priorities discussed during the preassessment planning phase and those that emerged through child assessment.
- Ongoing review of program plans. Progress on child and family outcomes is shared during ongoing, informal home-school contacts and is formally documented during one annual review conference.

Evaluation of the FISC project outcomes in the St. Cloud schools has indicated that family involvement in goal setting for students increased as a result of the process. Family members alone or collaboratively with staff identified 56% of the goals on the students' IEP/IFSPs. This is a shift from the typical IEP process, which research has described as usually child-centered and directed by professionals, with parents passive participants. This and other findings indicate that the FISC model is an effective process for increasing family involvement in the provision of educational services to children with disabilities.

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Family-School Collaboration in Interventions

by Michael Bloomquist

A strong link between child, home, and school can enable professionals to more effectively provide services to children with a wide range of needs. One service area in which a collaborative model is being developed is a school-based intervention approach to treating children with Attention-Deficit Hyperactivity Disorder (ADHD). The Minnesota Competence Enhancement Project (MnCEP) at the University of Minnesota is linking children with ADHD, parents, and teachers in a common treatment focus and evaluating the longterm impact of this intervention approach.

■ Needs of Children with ADHD

Children with ADHD have primary problems in impulsivity, maintaining attention, and hyperactivity. Many have secondary difficulties related to behavior problems, social and family problems, and academic failure. They are at risk for developing mental health problems, school related difficulties, and problems in the community. Individuals in the environments of these children (e.g. parents, siblings, peers, teachers) are often negatively affected by them.

Given the many challenges faced by children with ADHD and the others around them, interventions need to be comprehensive. Medications are frequently used as a primary treatment and are helpful, but by themselves are not sufficient. It is essential that these children develop competence in social-emotional functioning.

As a therapist, I believe a partnership between children, parents, and teachers is essential to promote social-emotional competence development in children with ADHD. When parents and teachers are communicating and working together - rather than in isolation or even in competition - the child's potential for learning is greatly enhanced.

■ Helping Children Develop Competence

Children with ADHD are often delayed in social-emotional development and do not comply with adults' directives or understand and follow the rules set up by adults. For many, it is necessary to train them to comply by using behavior modification techniques. These particular procedures involve parents and teachers administering positive and negative consequences to a child contingent on behavior. They provide external guidance and control for a child as a first step toward internalizing skills and competencies.

After children with ADHD have developed the capacity to comply and follow rules, training in problem-solving is often desirable. The basic idea is to teach children to think before they act. Problem-solving involves the steps of defining the problem; generating alternative solutions; examining the consequences of solutions; and selecting, implementing, and evaluating a particular solution. Children can be taught to apply problem-solving in different contexts. With the guidance of parents and teachers, training in problem-solving can help children develop the ability to regulate their own behavior. Additional training can help them regulate strong emotions, learn specific social behaviors, learn to apply problem-solving to social situations, and develop skills to successfully complete academic endeavors.

■ Helping Families and Teachers

It is essential to actively involve parents and teachers in the intervention process. At first it may be important to help these adults examine and change their own thoughts/beliefs (e.g., "He's a brat," "She does it intentionally," "I give up") and behaviors (e.g., giving in to the child's noncompliance, yelling, inconsistent discipline) towards children with ADHD. Even though the parents and teachers are not the cause of these children's problems, their thoughts/beliefs and behaviors can exacerbate their difficulties.

Parents and teachers play a vital role in intervening with children with ADHD. They are the primary people who conduct a behavior modification program. They can also be trained to model, prompt, and reinforce problem-solving, strong feelings management, and social and academic skills with children in the home and school environments. It is most effective if parents and teachers target the same skills for development, and use similar methods with a child.

Several interventions are unique to families. Parents of children with ADHD are often stressed out. Specific training in stress management for parents is often a necessary first step. Also, ongoing family interactions are often negative in families of children with ADHD. Therefore, it can be very helpful to train them in family problem-solving, communication skills, and conflict management skills.

■ Conclusion

A stronger link between child, home, and school is essential in serving children with ADHD or other conditions requiring interventions. The MnCEP project is developing a model for future interventions for these children, a model that draws on all the resources in a child's environment to help meet the needs of that child and their family.

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Life Planning for Adult Health Care

by Timothy W. Jorissen

Twenty or thirty years ago, the concept of life planning for families with a child who has a severe chronic illness or disability was of rather limited concern. Tragically, most of these children did not survive beyond adolescence. Advances in medical science, practices, and technologies have changed all that. Currently, 84% of children with chronic conditions now survive to adulthood. That development, plus the dramatic shift for many of these children from institutional care to community, family-centered care and services, have not only opened up many choices for families, but have presented issues and challenges. Life planning has become a significant concern for these families and a key factor in their quest for family empowerment.

A major aspect of life planning facing families with adolescents or young adults with chronic conditions is the transition from pediatric care to the adult medical system. It is one of two facets of life planning that this article will briefly highlight. The other, advance directives, may be viewed as the other side of the spectrum of the adult care system. Advance directives are legally recognized documents that either spell out a patient's wishes as to health care should he or she lose decision-making capacity, or designate another person to make such decisions for the patient. Both issues are highly emotional ones, but once faced, tend to be very empowering for the parents involved and the young person with a chronic illness or disability. To be faced successfully, both issues require considerable and sensitive support from professionals in the health care system.

■ Transition to Adult Health Care

Why should families be concerned about transition? If pediatric caregivers are achieving such impressive results with children with special health needs, why should those youth "move on" when both they, and certainly their families, feel comfortable in the pediatric setting? Indeed, there is great ambivalence within the medical profession itself about transition. Many pediatricians have very strong ties to their young patients and their families, and find it very hard to see them leave. On the other hand, internists and other adult caregivers often see these patients as immature, with conditions that they have little or no experience in treating. Often their parents are viewed as overly involved and far too demanding. Given all those barriers to transition, one could honestly ask whether it is worth the trouble. For a variety of reasons, and mostly from the developmental perspective of the adolescent or young adult, successful transition to the adult health care world is indeed worth the struggle.

A major reason to encourage transition is limitations in the pediatric setting. While pediatricians may well be experts in treating childhood diseases and disabilities, they are much less skilled in addressing the medical needs of adults. No doubt it is difficult for both parents and pediatricians to view these children, now grown up, as adults. That is, however, exactly either what they are becoming or, in fact, now are. And as adults, they will have adult disorders and other adult concerns, such as sexuality, reproduction, and vocational and financial aspects of care decisions that may have nothing to do with the childhood condition for which pediatric care was first sought. Secondly, and perhaps most importantly, continued care in a pediatric setting may seriously undermine the adolescent or young adult's own psychosocial development. Very often, pediatric caregivers have an almost impossible time switching from the parents as the real center of responsibility to the young adult. Not being taken seriously as an adult has an uncanny, self-fulfilling way of keeping the young adult patient a child and can seriously impede the development of adult independence and self-sufficiency. Lastly, continued care in a pediatric setting can send a very negative message that the many hassles of and barriers to transition are just not worth the trouble. This message, especially devastating when the chronic illness or disability is severe and, in fact, the mortality rate is high, is that the young person may not live long enough to make the transition worth the effort. As mentioned above, expectations like these tend to be self-fulfilling, and the young adult may decide that they are expendable since they are living on borrowed time.

The positive aspects of successful transition from pediatric care to the adult care system are numerous. Without doubt, it promotes normal development and independent behavior and self-reliance, all crucial to a young person who was likely very protected by his or her family as a child. Accepting a greater responsibility for their own health care decisions also tends to improve compliance with therapy and medication regimens by young adults. A positive transition experience can help young adults feel that they, indeed, have futures and it can be an incredible impetus to begin planning long-range life goals. The growth and development of children with chronic illness or disability should, ideally, approach that of the healthy adolescent as much as possible. For that healthy adolescent, the normal patterns of development involve the transfer of care from pediatricians to the adult care system. While certainly it may not be as smooth, that same transition philosophy and process should also apply to youth with special health care needs.

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Health Issues and Placement Decisions for Older Persons with Disabilities

by Deborah Anderson and Eric Kloos

Older people with developmental disabilities are the fastest growing age group among people with developmental disabilities. This trend, due primarily to improvements in health care and social service programs including residential services, is expected to continue into the foreseeable future. It is estimated that people 65 and older comprise approximately 12% of all people with developmental disabilities, similar to the nonhandicapped population.

The primary placement for people with developmental disabilities over 65 years of age has traditionally been nursing homes, far exceeding placements in state institutions and community facilities. The Omnibus Reconciliation Act-87 (OBRA-87) mandated review of nursing home placements of people with developmental disabilities is expected to exert significant pressure upon the existing system of residential care to absorb sizable numbers of persons currently living in nursing homes. In addition, the increased emphasis on family caregiving in recent years has resulted in unknown numbers of people with developmental disabilities living at home with aging parents who are, or soon will be, facing placement decisions.

> ...unknown numbers of people with developmental disabilities living in the community with aging parents...are, or soon will be, facing placement decisions.

These trends underscore the need for more specific knowledge upon which to base future planning for this age group. One of the issues that becomes critical is health status, which includes health conditions, types and extent of medical and related care received in different settings, issues faced by careproviders in caring for this age group when health care needs arise, and the capabilities of the residential service system to address these issues.

A study conducted by the Center for Residential and Community Services at the University of Minnesota in 1985-86 (Anderson, Lakin, Bruininks, & Hill, 1987) sampled 10% of all facilities owned, operated, or licensed by developmental disabilities agencies and having at least one resident over the age of 62 years with mental retardation. This included foster care, group homes (3-15 residents), large private facilities, and large state operated facilities. One or, if possible, two older people were included per facility, for a total of 370 individuals from 235 facilities. Information about residents was obtained through questionnaires completed by primary caregivers.

A follow-up study (Anderson & Kloos, 1991) was conducted in 1990-91 with the original sample of 370 persons to determine whether changes had occurred over time in residents and/or practices. In addition, the National Nursing Home Survey of 1985, which provides the most extensive information available on persons in nursing homes in the United States, was examined to determine the health status and services received by older persons with mental retardation living in nursing homes.

These studies revealed that nursing home residents with primary diagnoses of mental retardation, aged 65 and older, typically were less health-impaired than their same-age peers without mental retardation living in nursing homes. The former had a significantly lower prevalence of mental illness of an organic nature, Parkinson's, heart disease or other circulatory system disorders, respiratory disorders, arthritis and nonspecific disorders upon admission. There were no differences in the prevalence of diabetes; endocrine, digestive, or genitourinary disorders; or psychosis. They were more likely to have had epilepsy and "other nervous system disorders". These differences persisted, and were similar at the time of the survey.

Given their lower level of chronic disease and health problems, together with other findings, it suggests that availability, rather than suitability, may be determining some of these nursing home placements, particularly in non-metropolitan areas. It also appears that some conditions are underreported among persons with primary mental retardation, including arthritis, allergies, and the need for glasses, which may exacerbate the "adequacy of services" issue.

In addition, the "climate" in these settings may be less positive than in mental retardation/developmental disabilities settings. For example, older people with mental retardation seem to be viewed as having poorer mental health than appears to be the case, given their markedly lower rates of dementia and lower rates of anxiety and depression compared with older people in general in nursing homes (only 17% were considered to have good mental health).

Lakin, Hill & Anderson (1991) estimate that over 22,000 people with developmental disabilities in nursing homes are 55 years of age and older, and that up to 75% could benefit from movement to mental retardation facilities. The opportunity for placement in smaller, community based settings, however, requires proactive planning in order to ensure an appropriate array of smaller, less restrictive residential alternatives. This is particularly true for rural areas, which tend to rely more on state hospitals and nursing homes than more urban areas. Among other benefits, other

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Learning to Let Go

by Ceci Shapland

When Mac, my 16-year-old son with mental retardation, became ill with an ear infection, I called the doctor, made an appointment, spoke for him during the office visit, and took the prescription handed to him so I could see that it was filled. Mac is also considered by society to be nonverbal, so I take care of these things. How was he going to express his needs in the medical setting? I never stopped to ask.

As we fell into a routine of medication four times a day I took the responsibility for remembering until, one day, preoccupied with other household responsibilities, I forgot. Mac, however, did not and brought the medicine to me at the correct time. I realized I had limited him in self care by my overprotective attitudes. I began to examine areas of self management and realized that Mac had several skill areas that he could independently perform and others that he needed only some support to perform.

Mac Shapland expresses his questions, feelings and preferences directly to health care providers by using his bliss board.

In addition, I became aware of the areas he would continue to need help with and started to identify a means of ongoing support for these tasks. This awareness did not come overnight; it came through a combination of Mac's personal quest for independence and the opportunity to read and learn about transition health issues as a result of the Speak Up for Health Program. Speak Up for Health is a program of PACER Center in Minneapolis. It offers workshops and materials for adolescents with chronic illness and disabilities and their parents on planning for transition to the adult heath care system and promoting independence in health care.

As a result of my growing awareness, I looked at the self-advocacy skills Mac already had. Even though he is nonverbal, he communicates very well. He uses a bliss symbol board for other community settings, and his personal sign language, hand gestures, and facial expressions leave little doubt to what he is feeling and thinking. He makes his opinions clearly known, and he rarely fails to identify his feelings. In addition, Mac is very well liked. Most people who meet him are impressed by his positive attitude and outgoing personality. He finds an advocate in any setting he enters within a short time. After some examination, it was clear to me that Mac already had some good self-advocacy skills. I just needed to allow them to be cultivated and to grow. I am sure any parent, after a brief time to reflect, could identify his or her own child's strengths, as well.

Today, preparing for visits to the doctor is quite different. In addition to promoting Mac's strengths, I try to be organized before a visit. What questions need to be asked? I help Mac practice asking them on his bliss board. I think it is important for him to be open and honest and express his feelings. I encourage him to think about how he feels, then we practice explaining it as clearly as he can. I try to help him organize his thoughts and to give details. We think about when he has certain symptoms, and what events correlate with the symptoms. We also talk about how important it is to follow the treatment the doctor prescribes and to ask questions about the treatment if he does not understand. Now, I make sure Mac does all the talking to the doctor and that the doctor speaks directly to Mac.

In a short time, I will honor Mac's request to go to the doctor by himself. I guess I am not ready to let go of everything, but since I have included this as part of our transition planning, it will be an ongoing process, like all the other facets of learning to live in the community. Because I am aware of the importance of transition planning in health care, it will be part of the evaluation process also. When we look at a residential setting, health care policy and health providers will be a part of the overall information I will research. Mac will never be totally independent in managing his own health care. But, as I designate a guardian to handle his finances, I can also choose a health advocate who will be a good spokesperson for him and will keep up with his health records.

There are so many pieces of the puzzle to fit together to ensure success in the community, and health care is an important one. I am glad that I learned about how to plan for health care now, so that Mac will have some good skills when he leaves home.

Note: Article adapted from Transition Link, November 1991, a Publication of PACER Center, Inc.

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Resources

■ Organizations

- **Arc-U.S.**
  500 E. Border Street, S-300, Arlington, TX 76010
  (800) 433-5255
- **Beach Center on Families and Disability**
  c/o Institute for Life Span Studies, University of Kansas,
  3111 Haworth Hall, Lawrence, KS 66045
  (913) 864-7600, Fax (913) 864-7605
- **Center on Families, Communities, Schools & Children's Learning**
  Boston University, School of Education,
  605 Commonwealth Avenue, Boston, MA 02215,
  (617) 353-3309
- **National Center for Youth with Disabilities**
  Adolescent Health Program, University of Minnesota,
  Box 721 UMHC, Harvard Street at East River Road,
  Minneapolis, MN 55455
  (612) 626-2825, (800) 333-6293
- **National Information Center for Children and Youth with Disabilities (NICHCY)**
  P.O. Box 1492, Washington, DC, 20013-1492
  (703) 893-6061, (800) 999-5599, (703) 893-8614 (TDD)
- **National Parent Network on Disabilities**
  Room 115, 1600 Prince Street, Alexandria, MN 22314
  (703) 684-6763
- **PACER Center, Inc.**
  4826 Chicago Avenue, Minneapolis, MN 55417
  (612) 827-2966 (voice /TDD), (800) 53-PACER (toll free for parents in greater Minnesota)
- **Parent Case Management Program**
  Institute on Community Integration, University of Minnesota, 103 Pattee Hall, 150 Pillsbury Drive S.E.,
  Minneapolis, MN 55455,
  (612) 624-4848, (612) 624-6830, Fax (612) 624-9344
- **Research and Training Center on Family Support and Children's Mental Health**
  Portland State University, Regional Research Institute for Human Services, P.O. Box 751, Portland, OR 97207
- **Technical Assistance for Parent Programs (TAPP)**
  Federation for Children with Special Needs, 95 Berkeley Street, Suite 104, Boston, MA 02116

■ Videotapes

- **Our Children, Our Hopes.** (1992). Focuses on needs and challenges facing African American families with a child who has a disability. **Speaking Up for Health: Young People and Their Parents Speak About Health Issues**. (1992). About young people and parents supporting self advocacy in obtaining health care. Available from PACER Center, 4826 Chicago Avenue S., Minneapolis, MN 55417-1098, (612) 827-2966 (voice/TDD), (800) 53-PACER (toll free for parents in greater Minnesota).

■ Publications

- **Making Futures Happen.** (1989). Mount, B. & Zwernik, K. A manual for Personal Futures Planning group facilitators. **It's Never Too Early, It's Never Too Late.** (1988). Mount, B. & Zwernik, K. An introduction to Personal Futures Planning. Available from Governor's Planning Council on DD, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155.

The following are published by the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, (612) 624-4512. Call or write for ordering information.

- **FISC Individualized Family-Centered Planning Process** (1992). McGrew, K.S. et al. Describes process to strengthen family-school partnerships, collaboration, and links between families and support systems.
- **Family Needs Survey Results: Responses from Parents of Young Children with Disabilities** (1990). McGrew, K., Gilman, C.J., and Johnson, S.D. Summary of results of interviews with 57 parents of children ages 3-10 with moderate to severe developmental disabilities. Identifies their needs, resources, and priorities. From FISC project.
- **Collaborative Teamwork: Working Together for Full Inclusion** (1990). A pamphlet describing the process and role of collaborative teamwork in inclusive education.
- **IMPACT**. A 16-24 page quarterly newsletter containing in-depth articles on research, practices, philosophies, and trends in specific focus areas. Available are feature issues on **Training of Direct Service Staff, Inclusive Education (K-12), Inclusive Education (Preschool), Family Support, Consumer Controlled Housing, Self-Advocacy,** and **Transition.**
- **Policy Research Brief**. A summary of research on policy issues affecting persons with developmental disabilities, including **Parent Attitudes about their Daughter's or Son's Residential Placement Before and After Deinstitutionalization (1989),** and **Living in the Community: Persons with Mental Retardation and Allied Medical Conditions (1990)**.

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plan, most often the Individualized Education Plan (IEP). In one respect, the parent's role in the IEP planning is the same as it was during the preschool years: to make sure the child has all the support he or she needs to grow, develop, and learn, and to make reasoned decisions in partnership with professionals to make sure those supports are in place. But there is a tendency to forget the other task that those same family members may be undertaking with the child's more typical brothers and sisters: to gradually foster and encourage budding autonomy and independent decision making for the child. This tendency may be due in part to the fact that some children with disabilities may not make demands for greater autonomy on their own, and in part to the mixed messages professionals send parents about their child's ultimate capacities for decision making. Those who are parenting need to be doubly conscientious about finding opportunities to foster independent decision making for their children with disabilities. This may range, for younger children, from providing more opportunities for small risks (climbing the jungle gym, giving a small allowance that the child can "blow"), and in the later years, providing increasing freedom, including attending their own IEP meeting and learning how to participate actively in that process. The role of professionals in this effort is to provide families with the resources and support to encourage greater decision making (e.g., teaching decision making skills to youngsters with disabilities), and to respect the level of shared decision making that the parents and child feel comfortable assuming within their family culture. During these years, both parents and professionals have their eye on the future: their joint roles are to work as partners to prepare this young person for life as an adult.

■ New Roles in Adulthood

The role of families in decision making for adults may vary widely across cultures. In some cultures, the patriarch or matriarch may retain a greater or lesser degree of power over children and grandchildren for a long time. In other cultures, primary decision making is transferred from the family of origin to the newly married couple as they begin to form their own family. Parents, now grandparents, may provide a variety of support ranging from monetary assistance to advice, but the bottom line is that the right to choose from among life options, and the responsibility to face the consequences of those choices, belongs to the adult.

For a person with a disability, the reality is that he or she may continue to need support for different life decisions. Parents' or other family members' tasks are to find the appropriate balance: to assist the adult in making and carrying out their own decisions as much as possible, while continuing to provide a sheltering circle that supports but does not choke. This can be tough; one person's support is another person's smothering. Professionals whose perceptions cannot accommodate different family cultures are in danger of labeling family members as "overprotective," or "failing to let go," or alternatively, "uncaring" or "abandoning." The joint role of professionals and families at this juncture is to clarify and define that balance, and to facilitate the dreams and potential of the young person with a disability. It is especially here that circles of friends and futures planning can come in handy. The fresh views and creative suggestions of a larger number of people can help everyone involved find a balance.

■ New Roles in Aging

The thought of aging can bring forth both positive and negative images. There is the thought of retirement: for some, an opportunity to explore new dreams and have adventures there had been no time for in earlier years, while for others it means a loss of identity and purpose. It may also mean the increasing risk of health problems and, for some, the transfer of decision making from the older generation to the younger.

For the family of a person with a disability, the worry about possible disability and dependence for aging parents or other primary caregivers may be compounded by the question of what to do with the adult child with a disability? The job of families, then, is to plan ahead and to decide, well ahead of any emergency, just who will take over the responsibilities of support when the parents or other family members can no longer do it. It also is important to plan for the fun part of aging, to assure that the person with a disability can achieve the "golden years" of an enjoyable life in retirement. Professionals and families have the joint responsibility of creating options and thinking about ways to continue the support that the family may have less capacity to provide as time goes by.

■ Conclusion

Certainly, the paradigm shift to person-centered, family-centered decision making is still underway. It's not completely clear just what the terrain will look like when all the dust settles. For that reason, the descriptions of possible roles presented here are nothing more than a murky outline viewed through the cloud of dust. But we can see enough to believe, when everything has settled down and the new paradigm is fully in place, that the uproar and uncertainty required to traverse the shift will be worth it.

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■ Advance Directives

Moving from transition to advance directives may strike the reader as a bit premature, but for the young adult who has a chronic illness or disability and their family it is an important and empowering issue. The Patient Self-Determination Act of 1990, which went into effect on December 1, 1991, provides that all health care facilities provide written information to patients over 18 years about their legal rights to make decisions regarding the medical care they receive, including the right to refuse treatment and to prepare advance directives. This is an issue that most healthy older adolescents don't face. Indeed, few middle-aged adults in good health give the need for advance directives much attention. The federal legislation was obviously directed at the older generation who needed to face end-of-life care decisions. But, for older adolescents or young adults with serious chronic illnesses that have high mortality rates, advance directives are a most relevant concern and one which they and their families should address.

As with many issues in life, very often acknowledging the need to make a decision is as important as the decision itself. That is probably the case with advance directives. The most beneficial aspect of the Patient Self-Determination Act of 1990 for older adolescents and young adults with a chronic illness or disability may simply be that it helps them face the issue and encourages the beginnings of a dialogue between them and their families and other significant persons in their lives, such as professional caregivers. No one, of course, can ever tell another what is a proper end-of-life care decision. However, helping an adolescent with chronic illness or disability to face the issue in an open and supportive fashion is tremendously empowering, not only for the adolescent, but for his or her family and the professionals involved in the adolescent's life.

■ Conclusion

In a sense, the fact that transition to adult health care and advance directives have become issues today for families with children with chronic illness or disability is a tribute to a health care system that has made significant technological strides in a single generation. Dealing with these highly emotional issues certainly presents new and difficult challenges. However, for the children with chronic conditions who now survive into adulthood and their families, facing such issues can, and hopefully will, be seen as life-affirming and often empowering experiences.

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research has found a greater degree of community integration in community as compared to institutional settings.

The findings for residents living in facilities licensed by mental retardation/developmental disabilities agencies reveal that the incidence of chronic health problems was similar to, or lower than that noted for their same age peers without mental retardation living in the community. The most common chronic health problems were high blood pressure, arthritis, and heart disease, similar to this age group in general. Alzheimer's was infrequently reported. Nursing care declined from 1985-86 to 1990-91 in the sample studied, with residents of large facilities receiving the most nursing care. The most commonly noted age-related changes were that the resident had less energy/stamina and physical/health changes (e.g., general health decline or problems in walking/arthritis), noted by less than one-quarter of respondents. Few foster care and group home providers indicated "many or significant" health-related limitations for the residents in their homes, and only one-third of state facility providers indicated this level of limitation. Although routine health care did not seem problematic for most, there often was little planning or capability for handling medical emergencies. As a result, many older people were more at risk of nursing home placement when emergencies did arise or at times even prior to an emergency.

Overall, it appears that a substantial number of people currently living in institutional settings, including nursing homes and state facilities, are not sufficiently in need of medical services to warrant being removed from the community. Without concerted planning, however, they are unlikely to enjoy the benefits of community living, and without flexibility within the system to respond to occasional medical needs, their tenure in the community may be jeopardized.

References:

Anderson, D.J., Lakin, K.C., Bruininks, R.H., & Hill, B.K. (1987). A national study of residential and support services for elderly persons with mental retardation (Report No. 22). Minneapolis: University of Minnesota, Department of Educational Psychology.

Anderson, D.J., & Kloos, E.T. (1991). The 1985-86 Center for Residential and Community Services elderly survey follow-up. Unpublished raw data.

Lakin, K.C., Hill, B.K., & Anderson, D.J. (1991). Persons with mental retardation in nursing homes in 1977 and 1985 national nursing home surveys. Mental Retardation, 29 (1), 25-33.

National Center for Health Statistics (1987). Strahan, G. Nursing home characteristics: Preliminary data from the 1985 National Nursing Home Survey. Advance Data from Vital and Health Statistics, No. 131, DHHS Pub. no. (PHS) 871250, Public Health Service: Hyattsville, MD.

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questions. However, when I asked some of my teachers to read me the test questions, they would just pat me on the head and tell me to do the best I could.

Some days my body felt terrible. I would be so agitated inside from trying so hard that I would get sick to my stomach and throw up at school. Other times I would anxiously swing my foot back and forth to release some of the tension; then I would be reprimanded for not sitting still. In junior and senior high, I would take home books from every class and study until 2:00 and 3:00 in the morning, looking up almost every word in the dictionary. But when I turned in the paper, although the teacher said the content was good, I would still get a D or fail. I would stand and watch the teacher destroying my paper with big red "Xs" for misspelled words and incorrect punctuation. After years of this, I finally thought to myself, "I don't have to stay up until 3 o'clock in the morning studying to get a D or fail." So I would bring my books home and just leave them lying on the radiator.

Deep inside of me I wanted to learn so badly, but no one at school seemed to care. I think if it had not been for my family, who were always so helpful to me, I could have become emotionally and behaviorally troubled. But my mom always read to us, and stopped whatever she was doing to listen to our problems and help us solve them. My sisters and brothers always tried to help me and never in my life did I hear them call me a mean name. It was the discussion around the dining room table that taught me most of what I learned of geography, literature, science, and world affairs, and the family singing around the piano and playing classical, jazz, and pop records that taught me music. My life experiences taught me math and my mom, dad, sisters, and brothers taught me how to read.

I cannot fail to mention the two women who, in addition to my family, played a significant role in helping me learn to read and write. My Sunday school teacher had me read aloud every week in class, and my religious instruction teacher came faithfully to our house every Thursday to teach me to read and write from the Bible. I don't want to imply that I learned nothing in school. I was just unable to put my schoolwork into required written form or take written tests without assistance. This is the primary way that schools taught and still teach, so I "failed" according to their standards.

I am also a parent of a child with disabilities, whom I will refer to as Chris for the sake of privacy. The difference between Chris' educational experience and mine is that Chris was diagnosed as having learning disabilities and challenging behavior, and received many services that were not available to me. Although I knew that Chris needed these services because of the nature of the disability and this child's early life experiences, I was scared to death for my child each time that I had to ask for another service. I did not want Chris labeled because I did not know how it would affect this child's future.

It all fell apart when a colleague of our family doctor recommended that we send our 4 year old child to a treatment center for three weeks with the idea of getting a comprehensive diagnosis. To the horror of my child and our family, they ended up keeping Chris for nine months and, "in the name of therapy," intentionally destroyed the bond between mother and child, as well as destroying the bond between Chris and Chris' siblings. In the face of being threatened with court action to determine us as "unfit parents," we were forced in the end to kidnap our child because we had no other means of getting Chris back.

As time went on, I knew I really could not get around providing Chris the opportunity to receive support because this child's need was so great. It was apparent to the schools, it was apparent to the community, and it was apparent to my family that there was something wrong. I felt that I could either deal with my fear and get some help while I had some control over the situation, or I would end up abdicating my control to others and losing it forever.

With this in mind, I reinitiated a long process of seeking help to meet Chris' needs as well as mine. What I confronted was a community that did not understand, and a family (except for my brother) who thought my parenting skills were nil and they could do it better. Family members said things such as, "You're not being consistent," "You need to spank more," "You shouldn't spank," "You should take away privileges," "Sit your child down and talk straight," and "You just don't know how to raise kids!" At church, I just got raised eyebrows and eventually stopped going. Some of the neighbors were supportive and would come running whenever I needed help. Others criticized and snubbed me.

Because we were so traumatized by the events that I described, we desperately needed mental health care. Yet due to our financial circumstances, we did not qualify for any public health care, nor did we have enough money to pay for ongoing private care. So, we slipped through the cracks. The counseling support we received was very fragmented. Just when we would begin establishing some level of trust with our counselor, my husband's employer would change providers and we would have to start all over again. Added to our layer of frustration was the lack of minority doctors and counselors employed by the major health care providers. The counselors would say to me: " I can't relate to what it must be like when you feel hurt because of issues regarding race or cultural differences." Although I appreciated their honesty, I was still no closer to getting any help with our issues and concerns. After several encounters of this kind, our family could take no more.

My experiences with community organizations have been mixed. I have found that generic agencies, like the YM/YWCAs and Boy/Girl Scouts, were unable to meet the needs of my family in serving my child with special needs. When I would call asking if they could handle someone who would need extra care or supervision, their answer was no. This left me with no recreational activities for Chris outside

of what I could provide. I never felt such hurt in my life as when I watched other children, including Chris' sister, participating in community programs when Chris was left out.

In contrast, some of the community organizations were wonderful and were very supportive. One agency in particular, a child guidance center, provided help through positive reinforcement to my child and myself. They taught us ways to deal with Chris' disability, they tested Chris to find out which ways Chris learned best, and they taught Chris appropriate ways of dealing in social situations. Most of all, they gave me much needed time alone. Many times a hyperactive child requires so much attention and monitoring that you cannot leave the child alone for one minute without fear for his or her safety. Therefore, primary caregivers have little if any time to take care of their own needs. What was so helpful about this agency was that they recognized and attended to my needs - providing daycare for a few hours a week, allowing me to take a time out - which was essential for me to be able to be helpful to my child and family.

Despite all our troubles, Chris has since graduated from high school and is looking into college programs. What I see today in the schools are teachers who adapt to students' different learning styles and special needs in order to help them achieve success. It makes me wonder what I could have become if I had received the kind of educational support many youth are getting today. Currently, I have a job working with a program helping others to address some of the unmet needs that my family experienced. Hopefully, we will be able to prevent some of the dehumanizing experiences that we faced from happening to others.

As a result of my experiences there are several things I would like to say to professionals, families, and elected officials. First, to professionals I want to say that when a family is in crisis, they seldom have the energy or resources to wage a battle to get the needs of their family met. So I would ask agencies to take a hard look at how they provide services and encourage families to come out of their homes to get the services. Many families are frightened of sharing the negative things that are happening to them and of the far reaching consequences of documentation. Families want to be respected, treated with dignity, and listened to in the sense that they want their ideas about what is best for the child to become part of the treatment plan.

Secondly, to families I want to say that you do the best you can. You may feel scared to death at times at having to trust people that you don't know. However, you may have to deal with your fear and get the help that your child needs while you have some control over the situation. Otherwise you may end up abdicating all your control to others. You have to trust enough to get the help, but protect yourself and family by demanding from professionals what is best for you and your family as you see it. Stand your ground when you think that something they are suggesting would be detrimental. Hang in there! There is light at the end of the tunnel.

Lastly, to elected officials I want to say that down through history societies have been judged by the way they treat the most needy of their people. When we are dealing with human beings and money, we have to make a distinction between which one is the most important. There is an old saying: "You take care of your own first, and if you don't you are worse than an infidel and you have denied the faith." With this in mind, I wish to have you take a deep look at what is happening to human beings in our country. I see too many people concerned with saving money and short term gains at the expense of human dignity and future well being. We can either deal with comprehensive programs that empower people now to take care of themselves with dignity and sense of self worth, or end up losing the most important "commodity" we have - our young and ultimately our future.

Vivienne Kaufman is a Home-School Liaison with a public school system in the Midwest.

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it was for her father and he was trying, even though he was not very good at it.

Was this worth mediation? Without the common understanding that came in the mediation discussions, the parents and daughter probably would not have moved so quickly from their positions and the frustration that was coloring their views of each other. The daughter was successfully diverted from juvenile court. The mediator demonstrated a new means of resolving conflict, and since it worked there is a good chance that the model might be adopted for use in their home.

In many family mediations, children believe that they are not being heard and/or that they are not being treated fairly. Parents trend to be frustrated because their child has become obstinate and they cannot figure out how to change the child's behavior. Each gets angrier and guiltier, and comes to suspect whatever the other says. At this point, the family becomes paralyzed, and intervention is needed if the conflict is to be ended soon. Sometimes what is wanted by parent or child is very simple, but as with the father mentioned above, no one ever showed the family how to get what they needed in an appropriate manner.

One mother wanted her son to attend school and stop fighting with her. She also wanted to know that he loved her. This was hard for her to admit, but in mediation she finally said shyly, " I'd like you to give me a hug or say you love me once a week." Her son agreed. It sounds so simple as I write it, but for the family it was a large step. They did not know how to communicate well about what they wanted from each other. In mediation they tried communicating and it worked. That is the goal of mediation, to get communication working so that families can resolve their own problems, first in mediation and thereafter on their own.

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IMPACT: Feature Issue on Family Empowerment
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The mission of the Institute is to apply its resources to improve the quality and community orientation of professional services and social supports available to individuals with disabilities and their families. Efforts are directed at facilitating the independence of citizens with disabilities and their social integration into the mainstream of community life.

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